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ABSTRACT

The project evaluated the need to include nutrition services in North Carolina's Developmental Disability (DD) Programs. Six major evaluation efforts were undertaken: (1) surveys of nutrition care providers within the state and specialists nation wide; (2) site visits to facilities and clinics; (3) a random review of 135 charts from developmental evaluation centers; (4) computerized dietary analysis of 25 children participating in the Crippled Children's Services (CCS) Program; (5) a review of management information and program statistics; and (6) a review of scientific literature on nutrition intervention in the care and treatment of developmental disabilities. Among major findings were that all of the 25 CCS participants had less than optimal nutrient intakes; 94% of developmental evaluation center administrators indicated inadequate nutrition counseling and evaluation; few local public health nutritionists have participated in a CCS client evaluation; and existing regional nutrition consultants do not have enough time to become involved in direct service to DD clients. Recommendations are offered for model implementation and funding for interagency cooperation. (CL)

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ASSURING NUTRITION SERVICES TO NORTH CAROLINA'S DEVELOPMENTALLY DISABLED CHILDREN

Final Report

Gina M. Ries, M.S., R.D.
Principal Investigator

Funding Period: 2/1/84 to 9/29/84

Submitted to:

Developmental Disabilities Branch

and

Nutrition and Dietary Services Branch

Of The

Maternal and Child Care Section
Department of Human Resources
State of North Carolina
through the

Division for Disorders of Development and Learning (DDDL)
University of North Carolina at Chapel Hill

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TABLE OF CONTENTS

Page

ACKNOWLEDGEMENTS i

TABLE OF CONTENTS 1

I. PROJECT OVERVIEW 2

A. Introduction 3

B. Program Goals and Objectives 5

II. EXECUTIVE SUMMARY 11

III. JUSTIFICATION FOR NUTRITION SERVICES IN DD PROGRAMS 16

A. Evidence of Need from Past Pilot Endeavors in North Carolina . . . 17

C. Nutrition Risk Factors Defined 34

IV. RECOMMENDATIONS 37

A. Recommendations to Agencies 38

State DD Branch 38
State Nutrition and Dietary Services Branch 40
The State Division of Health Services 41
The DDDL 42
Local DECs/CCS Clinics 43
Other Agencies 45

B. DD Nutrition Program Plan: Goals and Objectives 46

C. Suggested Inclusions in Nutrition Positions Descriptions 49
State Nutrition Coordinator 49
Regional (Direct Service) Positions 51

V. PROJECT BIBLIOGRAPHY 53

PROJECT OVERVIEW

Introduction

The North Carolina Division of Health Services, through their Developmental Disabilities Branch, and in cooperation with the Nutrition and Dietary Services Branch, elected to use special 1983-84 federal Job's Bill money to contract for completion of a statewide evaluation and planning project involving nutrition services. The purpose of the study was to determine the need for and method of implementation of nutrition services into the state-administered developmental disability programs offered to mothers and children in North Carolina. This document is the final report resulting from that evaluation and planning project.

Specifically, the study involved a review of programs administered by the Developmental Disabilities Branch, with emphasis on the federally funded Crippled Children's Program (CCS), a network of 19 Developmental Evaluation Centers (DECs) supported by a combination of federal, state and local monies, and to a lesser extent the Genetic Counseling Program. A review of public health nutrition operations within the state was undertaken as well, in order to best determine integration or service exchange potential for the future. Those already existing nutrition services in North Carolina are centered in the 100 county health departments and the 4 regional offices of state government. The regional offices offer mainly local consultation but some provision of direct service as well.

Other state programs operated by the Division of Mental Health, Mental Retardation and Substance Abuse Services, Department of Human Resources, and by the Department of Public Instruction, to serve essentially the same handicapped child population with similar magnitude and impact, were also reviewed. Examples of some of these closely related services include the public school system's educational service to exceptional children (including the handicapped), a network of developmental day care centers, and the state's residential treatment/care centers for handicapped children. Various other organizations, programs and individual activities more peripherally involved were also reviewed as a part of the needs assessment process and are discussed in the course of the report.

The consultant contracted to carry out the evaluation, an individual with past experience in the administration of statewide nutrition programs, was housed at the University Affiliated Center, Division for Disorders of Development and Learning, University of North Carolina at Chapel Hill. Approximately 8 months were spent in the design and conduct of the evaluation described herein. A combination of research, monitoring and evaluation techniques were employed in an attempt to complete a thorough assessment of the need and possibilities for enhanced nutrition service. Recommendations and plans for needed program enhancement are included herein as the final outcome of the study.

This concentrated effort toward the expansion of nutrition as a demonstrably viable service within state and federally funded health programs appears timely and unique. Although the Crippled Children's Program (CCS) has been nationally operational since 1935, a nutrition component per se has never been mandated. Thus, strides in the provision of quality nutrition care to handicapped children have come piecemeal from varying individual state CCS

Programs and dedicated nutrition specialists around the country. However, a unifed, national attempt to justify inclusion of a nutrition service within the Federal CCS legislation has yet to be undertaken. Now, with the advent of block grant legislation, comes the opportunity for individual states to initiate and incorporate their own variations and standards into federally funded programs. Secondly, in this time of tightened cost management and heightened interest in preventive medicine within health care programs both public and private, the lack of existing, documented evidence of need and cost/benefit for many of the health specialties, nutrition included, becomes more apparent. Thus, this particular effort to document need, produce evidence of effectiveness of a nutrition service, and evaluate comprehensively the possibility for such within existing developmental disability program operations is critical and timely.

Hopefully, the information contained in this final report can be of assistance to administrators of developmental disability and/or nutrition programs at the local, regional and state levels in North Carolina. The study was also undertaken and has been designed to serve as a nutrition service needs assessment model for use, if applicable, by planners and evaluators of Crippled Children's, Developmental Disability, and public health nutrition programs in other states.

The goals of the project, the objectives specific to each of those broad goals, and the various phases of the project, are described on the following six pages.

ASSURING NUTRITION CARE TO NORTH CAROLINA'S HANDICAPPED CHILDREN

PROJECT GOALS

1. To assess the quantity and quality of nutrition services currently being provided to North Carolina's handicapped children.

2. To identify the nature and extent of unmet nutrition service needs to the same population.

3. To provide information to administrators regarding the cost vs benefit (outcome) of meeting the unmet needs which are identified.

4. To suggest a plan for improvement of nutrition service delivery to this population at the local level.

5. To gather and translate into practical format, the expertise and tools required for thorough nutritional evaluation of the handicapped individual.

6. To provide national leadership in documenting the need for and planning for the implementation of quality nutrition services within federal and state funded developmental disability programs.

PROJECT OBJECTIVES

GOAL 1: TO ASSESS THE QUANTITY AND QUALITY OF NUTRITION SERVICES CURRENTLY BEING PROVIDED TO NORTH CAROLINA'S HANDICAPPED CHILDREN

a. A needs assessment composed of the following 7 components will be completed by August 1, 1984:

i) survey of Developmental Evaluation Centers (DECs) (perceptions/interests/attitudes)*

ii) survey of local public health nutritionists (perceptions/availability/expertise/insight)*

iii) survey of regional nutrition consultants (documentation of need/existing services)*

iv) survey by regional nutrition consultants (documentation of need/existing services)*

v) survey of non-nutrition regional consultants (insight)*

vi) survey of 50 state Crippled Children's (CC) nutritionists nationwide (standards/state of the art)*

vii) survey of 28 University Affiliated Facilities' nutritionists nationwide (standards/state of the art)*

viii) monitoring of at least 10 of the 19 DECs by standardized format (documentation of existing level of service)*

ix) chart review and tracking of at least 50 high-nutrition-risk DEC clients (documentation of existing level of service)*

b. Written interpretation of the needs assessment, including discussion of the following issues, will be completed by September, 1984:

i) interest in, attitudes of DEC administrators toward enhancement of nutrition services

ii) the need for education of non-nutrition professionals regarding the expertise, contribution to be made by nutrition(ists)

iii) the feasibility of using existing local public health nutrition positions to service nutrition needs of handicapped children

* The issues relative to establishment of a DD nutrition component which were explored with each of the various groups.

iv) existing arrangements for the provision of nutrition expertise to DD children

v) availability of standardized tools which could contribute to the quality of nutrition services to N. Carolina's handicapped children

vi) the comparability of N. Carolina's level of expertise in meeting established need to that of other states'.

GOAL 2: TO IDENTIFY THE NATURE AND EXTENT OF UNMET NUTRITION SERVICE NEEDS TO THE SAME POPULATION

a. A compilation of relevant statistics regarding cost of nutrition services vs. cost of other aspects of DD, CC care, — and an attempt to numerically demonstrate the cost/benefit of the former will be completed by August 1,1984.

b. Case evidence of not less than 50 instances where nutrition service needs were left unmet and the resulting outcome to date will be recorded by August 1, 1984.

c. A system for identifying DD children in need of nutrition services will be devised by June 1, 1984; the identification system will then be applied to 250 randomly chosen case records to determine the percentage of children who theoretically should have had a nutrition consultation. Results will be documented by August 1, 1984.

d. Nutrition assessments will be carried out and documented on at least 25 DD children who would not otherwise have seen a nutritionist, to provide examples of nutrition's potential contribution to the quality of care. To be completed by September 1, 1984.

GOAL 3: TO PROVIDE INFORMATION TO ADMINISTRATORS REGARDING THE COST VS. BENEFIT (OUTCOME) OF MEETING THE UNMET NEEDS WHICH ARE IDENTIFIED.

a. A comparison of outcome differences among children and centers having nutrition expertise available vs. similar cases where nutritionists were not available will be made and documented by August 1, 1984.

b. A compilation of dollars spent via the Crippled Children's Program on various conditions designated to be high risk from a nutritional standpoint vs. the cost of providing a proposed future nutrition service will be made and reported by September 30, 1984.

c. A set of suggestions for deriving monies adequate to support needed nutrition services from existing budgets will be made for inclusion in the final report.

GOAL 4: TO SUGGEST A PLAN FOR IMPROVEMENT OF NUTRITION SERVICES DELIVERY TO THIS POPULATION AT THE LOCAL LEVEL.

a. A written plan for altering nutrition services to meet identified need, complete with dates and phases for implementation, will be drawn up on the basis of findings and recommendations, by September 15, 1984.

GOAL 5: TO GATHER AND TRANSLATE INTO PRACTICAL FORMAT, THE EXPERTISE AND TOOLS REQUIRED FOR THOROUGH NUTRITIONAL EVALUATION OF THE HANDICAPPED INDIVIDUAL.

a. A survey of 50 state CC nutritionists, and 28 UAF nutritionists nationwide will be conducted by May 1, 1984, with provision for the collection of any standards and standardized tools used by CC, DD nutrition specialists in other states.

b. All standardized materials to be recommended will be reviewed with the University of North Carolina's DDDL nutritionist and the State Health Department's DD nutrition consultant for determination of greatest usefulness, acceptability of format and inclusion in the final recommendations.

c. Identifiable commercially available materials will be reviewed for inclusion in a "recommended resources" portion of the final report.

d. Recommendations regarding the education and training best required of a professional providing nutrition service to handicapped children will be formulated by June 1, 1984, on the basis of state public health nutritionist classification guidelines and training opportunities available both in and out of state.

GOAL 6: TO PROVIDE NATIONAL LEADERSHIP IN THE DOCUMENTATION OF NEED AND PLANNING FOR IMPLEMENTATION OF NUTRITION SERVICES

a. Documentation and recommendations as a result of the evaluation study will be made verbally and in writing to the appropriate administrators within the State Division of Health Services by September 30, 1984.

b. The completed document resulting from this evaluation study, pending approval by appropriate N. Carolina administrators, will be submitted to federal nutrition specialists in the region and in the DHHS Central office, with mailings to other national, state and locally interested parties as appropriate.

PHASES OF THE PROJECT

I. DETERMINE GOALS AND OBJECTIVES	Tools for Accomplishing
Establish a process through use of existing guides.	DHHS "Nutrition Services for Children with Handicaps" "Meeting Nutrition Service Needs CC/ DD Clients"
II. CONDUCT NEEDS ASSESSMENT	
Determine interests, attitude, needs of DECs, as perceived by their administrators.	Preliminary survey of DEC Administrators
Establish incidence of already-documented conditions of nutrition risk in the DD child population.	Patient Record Review Form
Establish current staffing, funding, services, caseloads, practices, provisions of DECs and CC clinics.	DEC/CC Clinic Profile Questionnaire
Determine the current level of sophistication regarding provision/mode/documentation of quality nutrition services in the similar programs of other states.	UAF and CC surveys to other states
Utilize any pre-existing methods of documenting need for nutrition services.	Telephone conversations with other states
Gather evidence of improved outcome via nutrition services for specific DD Conditions.	Review of the literature
Determine the need for nutrition services to this population as perceived by medical directors and local program administrators.	Letters of support
Determine need for nutrition services based on outcomes of past pilot endeavors in North Carolina.	From reports of Elizabeth City and Wadesboro DEC pilot projects, the past survey of Dr. Hughes Bryan, the North Carolina Nutrition survey
III. IDENTIFY RESOURCES	
Establish the location, numbers, qualifications, time vs. caseload, availability, and perceived need for training, of the local public health nutritionists.	Local public health nutritionists' questionnaire

IDENTIFY RESOURCES (continued)	
Explore existing use and potential for future use of other health care team members in screening, referral, provision of some components of nutrition care.	DEC/CC Clinic Profile Questionnaire
Assist interested local agencies/clinics in the individual (temporary) arrangement of some immediate service to their clients by a nutritionist.	Local DEC/CC visits by the Project Coordinator
Determine funding situation in DD programs statewide, look for any possible opportunities to suggest an effective shift in monies to cover some enhancement in nutrition services.	Discussion with state DD office staff; DEC/CC Clinic Profile questionnaire; Discussion with local DEC/CC administrators
IV. DEVELOP A PROGRAM PLAN	
Define which conditions will be considered of sufficient risk to warrant a nutrition service.	Review of others' work and consultations with North Carolina DD nutrition specialists.
Present concrete recommendations to the various program levels, i.e., branches of the state division of health, existing and/or future regional nutrition specialists, interested local DEC/CC projects.	The written report and presentations to State branch heads. Presentation to NCPHA and presentations at Fall workshop.
Develop long range goals and objectives as appropriate.	The written report
Recommend options in in-state and out-of-state training that would qualify one to function in any specialized positions designated within the recommendations.	The written report following review of existing training opportunities
Provide a reasonably extensive listing of reference and educational nutrition materials to all potentially involved nutritionists and other interested health professionals.	The written report following review of existing references/materials

EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

Beginning in February, 1984, the State Division of Health Services, through the Division for Disorders of Developmental and Learning, the University Affiliated Facility/(UAF) at the University of North Carolina at Chapel Hill, undertook to evaluate the need for inclusion of nutrition services into the state's Developmental Disability (DD) Programs. The eight month nutrition service needs assessment included six major evaluation efforts. Those were:

1) a series of surveys to North Carolina DD and nutrition care providers, UAF and Crippled Children's (CCS) nutrition specialists nationwide.

2) Site visits to 15 facilities and/or clinics providing one or more services to DD children.

3) A random review of 135 charts from various developmental evaluation centers around the state.

4) Computerized dietary analysis of 25 children participating in the CCS Program.

5) A review of collective explanatory, budgetary and other management information and statistics available on numerous programs through state Central Offices.

6) A review of the scientific literature regarding nutrition intervention in the care/treatment of developmental disabilities.

The following are the major findings of the study:

• A total of $195,852,947 were budgeted for developmental disability programs in North Carolina in fiscal year 1984. Of that amount, an approximate $550,000 was spent on the purchase of salaried direct nutrition service (registered dietitian) providers. This represents 0.29% of the total budget; however, all of the dietitians are involved in institutional work at the State's five mental retardation inpatient care centers, funded through the State's Division of Mental Health, Mental Retardation and Substance Abuse. At least one fourth of those 22.5 full time equivalent dietetic positions are involved in the administration of the institutions' food services, rather than in nutrition education, counseling, or clinical assessment. The Division of Health Services does not currently fund any full time nutritionist position from it's $21,690,000 annual developmental disability budget.

• The Crippled Children's Program spent an average of $1041 per child enrolled in 1983-84. Of the 503 conditions for which the Crippled Children's Program will reimburse, 35% (164) are nutritionally related medical conditions, or have dietary alterations indicated as part of their treatment. Yet no nutritionists are involved in the staffing of any of the 126 CCS specialty clinics in the state, nor are nutrition consults/counseling a reimbursable expense.

• Of the 25 CCS participants receiving a computerized dietary analysis as a part of this study, 100% had less than optimal nutrient intakes. The most common problems were: excessive fat, sugar and salt intake, inadequate calories, a diet insufficiently nutrient-dense (i.e., inadequate in milk, vegetables, fruit, and/or meat), and extreme underweight.

• When CCS categories of reimbursable conditions are ranked by expenditure and number of children served annually, the category entitled "Endocrine, Nutritional and Metabolic Conditions ranks fourth out of 17 categories. Thirty-four out of the forty-seven conditions included in this category (72%) have been designated as diet-related in the course of this study. Neoplasms as a category rank third in number of children treated and dollars spent, and nutrition intervention is relevant to all seventy of the reimbursable cancer conditions. Diseases of the Digestive System rank ninth, with 164 children served and $151, 886 dollars spent last year. Diseases of the circulatory system were tenth in cost, and 33% of those conditions were found to have dietary alterations indicated.

• A survey of DEC administrators revealed that 94% of them acknowledge that the nutrition evaluation and counseling needs of their clients are not presently being met. Sixty-four percent of those relying on other health professionals to explore the dietary needs of clients were not satisfied with the quality of the nutrition evaluation, if any, being provided. Site visits as a result of this study reveal that in nearly every case, nutrition assessment and nutrition counseling are not being provided by any of the existing staff at DECs.

• Although nutrition counseling is listed as a possible need of clients on DEC computerized tracking forms, as a general rule, DECs are not evaluating clients to uncover nutrition need. Height and weight information is not always taken on every child. If taken, it is plotted on a growth grid only 50-70% of the time, thus eliminating comparisons against norms in at least one out of every four children. Hematocrits/hemoglobins are, in general, no longer done on children coming through DECs. In a significant number of cases neither a physician nor nurse will see a child as part of the evaluation, if medical problems are not the priority for that child. In general, most DECs ask few or no questions regarding diet, weight change, eating habits or feeding skills on their standard forms. The combination of all these factors make it likely, plus evidence from charts reviewed as part of this study confirm, that nutritional concerns are being overlooked and remain unaddressed. On occasion nutrition counseling is listed as a need of the client on state data collection sheets, and the receipt of this service, has, in a few cases even been documented during tracking. However, the tracking system and visits to DEC sites and with staffs fail to reveal how and by whom that documented service is actually being provided. By and large, however, nutriton counseling is not documented as a need.

• Of 135 client charts reviewed, with 105 of those coming from DEC files, 70% contained evidence of one or more nutritional needs/concerns (see pages 25-33). If the variable of merely having growth data available and plotted on a growth

grid are removed, as one indication of a need for service, 57% of the records contain even more apparent and serious evidence of nutritional need. If the charts of the 29 long term residential patients reviewed are removed from these statistics, leaving only DEC charts, 48% of those remaining still contain evidence of obvious nutritional need.

• Site visits to DECs and several other facilities provided detailed information regarding standard practices/future possibilities for the handling of nutritional needs.

• 64% of local public health nutritionists report that they work out of a county health department which also operates one or more Crippled Children's specialty clinics. Yet 96% of those nutritionists have never participated in a CCS client evaluation. It has not been within their job responsibility to do so.

• 56% of local nutritionists reported that, without further training, they would not feel comfortable in evaluating the nutritional needs of a handicapped child. The implication is that this is regarded as a specialty area within the field of nutrition, thus requiring a specially trained individual to adequately meet client needs. Twenty-one percent of local nutritionists indicated that even with adequate training, in light of their current job responsibilities, time would not allow for their involvement in CCS or DEC clinics. WIC and county health department funds account for those salaries, and job responsibilities obviously reflect that arrangement.

• Currently an approximate $225,000 are being spent annually on regional nutrition consultants employed by the Division of Health Services in the 4 regional offices of State Government. Their responsibilities do not include, however, consultation to any of the Division of Health Service DD programs, i.e., DECs, Genetics, CCS or the Sickle Cell Program.

• Survey results indicate that it is not feasible, with regard to time, to expect existing regional nutrition consultant positions to become involved in direct service to DD clients. Lack of time, a desire for further training in this area, and the question of the appropriateness of their involvement in any direct service, as reflected in existing job descriptions, were all identified as obstacles to such involvement.

• Two excellent endeavors of the past in the state have previously demonstrated the need for and/or benefits to be derived from nutrition counseling/care of DD patients. Dr. Hughes Bryan, in 1965, showed that the diets of approximately 46% of Crippled Children Service recipients surveyed within a ten county area of North Carolina, were inadequate. The 1972 North Carolina Nutrition Survey showed that in fact, the diets of 43% of all preschool children in the state were inadequate and that nutrition knowledge of the homemaker had the greatest influence on the quality of the preschool child's diet. And finally in 1979, a one year pilot project at the Elizabeth

City DEC in North Carolina established that 50% of the 103 children seen over a year's time had an inappropriate intake of one or more nutrients (see page 19-24).

• The DDDL, the designated training site in North Carolina for health professionals engaged in the care of DD children, is providing training to 10 or fewer nutrition students per year. On average the students remain less than one week, come one at a time, and are not there because of any definite plan to eventually work in the area of DD. Thus, the training ground could be more efficiently used as a source of DD-specialized nutrition manpower. The possibilities for establishing a formalized nutrition training practicum for individuals committed to specific, DD-created jobs upon completion of the training, exists in this State, through more effective use of the DDDL.

Tangible accomplishments as a result of this needs assessment include:

• The design of a standardized DD nutrition screening/referral form, adopted in concept from the State of Colorado, Division of Health Services, for implementation at DECs and CCS clinics statewide. The tool will insure adequate attention to nutrition/feeding issues by any health professional administering the 'screen' to a child-client. Some record of nutritional status will thus be available on every client, and a regular referral source can be established, which will further establish the exact level of demand for a nutritionist at a particular DEC or CCS clinic.

• A one-page listing of conditions which place a patient at high risk nutritionally. To be used in tandem with the screening form, the list will serve as a first and practical means of establishing the circumstances under which nutrition should be regarded an imperative issue in a client's care.

• A sublisting of the conditions reimbursable through the CCS program which are nutrition-related. This is to be dispersed to CCS specialty clinic staffs and county health department nutritionists for practical use in pinpointing:

a) CCS clinic participants in need of nutritional attention

b) Participants in county health department programs who are not now receiving special nutritional attention for their CCS-eligible medical condition. (Health Departments have some existing information regarding CCS participants in their county which will need to be used in conjunction with this new 'nutrition conditions' listing).

• A two day training workshop to North Carolina's public health nutritionists, offered through the University of North Carolina School of Public Health, and entitled "Assuring Nutrition Services to Developmentally Disabled Children". The workshop will be held September 6-7, 1984 in Chapel Hill: It was planned as a finale to this needs assessment study, and in response to the large number of requests which have come in the past for a training session on this topic.

• The recommendations on pages 37-52 for the consideration of appropriate administrators and, hopefully, eventual implementation into the DD programs of North Carolina.

JUSTIFICATION FOR NUTRITION SERVICES IN DEVELOPMENTAL DISABILITY PROGRAMS

Evidence of Need from Past Pilot Endeavors in North Carolina

Three studies have been undertaken in North Carolina in the past, two of them specifically with developmentally disabled children, which demonstrate the incidence of nutritional problems within this population. Dr. Hughes Bryan and associate published in 1965 the results of a home survey involving 164 children, all recipients of State Crippled Children's Services, living in 5 counties in North Carolina. The intent of the study was to learn the frequency of various feeding and nutritional problems within the non-institutionalized crippled child population for purposes of planning a nutrition component for the Crippled Children's Service. Dr. Bryan's findings are best summarized in Tables 17-20.

Of greatest significance was the finding that the diets of approximately 46% (Table 17) of the Crippled Children Service recipients surveyed were found to be obviously inadequate. Only 25% of those surveyed had diets judged definitely adequate.

Children with a variety of medical conditions were looked at (Table 20). Feeding and nutritional problems related to a child's particular physical handicap rather than a physical handicap itself per se were the most common occurrances affecting nourishment (Table 19). However, in 72% of the cases reviewed, poor diet of the entire family was cited as the underlying cause of the child's dietary inadequacy (Table 18). Dr. Bryan concluded that dietary and nutritional problems are sufficiently frequent in crippled children to support the recommendation that all such children should receive a nutritional evaluation and, when indicated, ongoing service (3).

The Developmental Evaluation Center in Elizabeth City sponsored a pilot project in 1979, with funding from the State Division of Health Service's DD branch, which involved placing a nutritionist on staff at the DEC for a period of 13 months. The pilot project was undertaken as a means of establishing the need for a nutritionist in the DEC setting. Details of the pilot endeavor have been described elsewhere (13); however, the most relevant findings are as follows:

(From Table 21)

- 103 clients with various diagnoses were evaluated by the nutritionist

(From Table 22)

- 50% of those 103 cases had an inappropriate nutrient intake
- 40% had a diet determined to be of "poor quality"
- 22% had an inadequate calorie intake
- 18% had an excessive calorie intake
- 19% had delayed feeding skill development
- 29% had no problem with diet

(From Table 23)

- 26% had an inadequate iron intake
- deficiencies of other nutrients in the diet were common

(From Table 24)

- 39% of the parents attended nutrition counseling/education services and appeared to understand the recommendations made
- 23% of parents reported making an attempt at following the nutritional recommendations made
- 10% of the parents appeared to have adopted the recommendation for use with their children
- in 7% of the children seen, appropriate physical changes such as weight gain, weight loss or improved feeding skills were seen

In addition,

- 7 requests for nutrition inservices workshops were received at the DEC and provided

Clearly, the results documented and listed above demonstrate the contribution/benefit to be realized through the availability of a nutritionist in a developmental evaluation setting.

If quality of the entire family's diet is an issue in the resultant nutriture of DD children, some mention must be made of the results of the 1972 North Carolina Nutrition Survey. Commissioned by the Governor, this intensive statewide survey examined the nutritional status of the state's population as a whole. Findings of particular relevance to the population commonly served through the Crippled Children's Program and DECs include the following:

- Three factors were found to be related to a family's dietary adequacy:

  household income
  formal education of the homemaker
  nutrition knowledge of the homemaker

- Of the three factors, nutrition knowledge of the homemaker had the closest relationship to the adequacy of diets of preschool children
- 43% of preschool children were found to have inadequate diets
- 27% of all households (approximately 1 in 4) were found to be consuming a nutritionally inadequate diet
- 28% of preschool children had an inadequate iron intake
- Dietary inadequacy occurred with greatest frequency among households with a:

  comparatively low income
  comparatively large family size
  comparatively large number of preschoolers in the household
  high percent nonwhite members

In a general sense, the findings of this third North Carolina based study would appear to lend credence to the potential need for enhanced nutrition services at least to the population served through the Crippled Children Program.

Table 17

Adequacy of the Diet of 164 Crippled Children

Diet Classification	Whites		Blacks		Both Races	
	No.	%	No.	%	No.	%
Obviously adequate	31	43.7	10	10.8	41	25.0
May be adequate	14	19.7	14	15.0	28	17.1
Probably inadequate	8	11.3	8	8.6	16	9.8
Obviously inadequate	17	23.9	58	62.4	75	45.7
Doubtful information	1	1.4	3	3.2	4	2.4
Total	71	100.0	93	100.0	164	100.0

Table 18

Cause of Dietary Inadequacy in 119 Cases Whose Diet Was Rated Less than "Obviously Adequate"

Cause of Dietary Inadequacy	Whites		Blacks		Total	
	No.	%	No.	%	No.	%
Poor family diet	22	56.4	64	80.0	86	72.2
Child's physical condition*	5	12.8	6	7.5	11	9.2
Other causes	12	30.8	10	12.5	22	18.5
Total	39	100.0	80	100.0	119	99.9

*Poor family diet was a contributory cause in ten of these children.

From: Bryan, Hughes. Dietary and Nutrition Problems of Crippled Children in Five Rural Counties of North Carolina. Am. J. Public Health 55(10), 1545-1554, October 1965.

Table 19

Feeding and Nutritional Problems Related to the Child's Handicap

	Cases
A. Physical inadequacies interfered with feeding	5
B. Other types of feeding and nutritional problems related to the physical handicap	11
C. Special preparation of food required	9
D. Obviously obesity	4
E. Disturbed interpersonal relations affected the food intake	9

From: Bryan, Hughes. Dietary and Nutritional Problems of Crippled Children in Five Rural Counties of North Carolina. Am. J. Public Health 55(10),1545-1554, October 1965.

Table 20

Summary of the Population, Sample, Interviews Completed and Cases Lost

Diagnostic Categories	Population	Sample	Interviews Completed	Lost to Study
Neurological				
Cerebral palsy	21	21	14	7
Other birth injuries	9	9	7	2
Other diseases of nervous system	7	7	3	4
Late effects of acute poliomyelitis	33	16	16	
Arthritis and Rheumatism				
Rheumatic fever, acute	11	11	7	
Rheumatic fever, inactive	3	3	1	4
Arthritis and rheumatism	5	5	5	2
Heart				
Chronic rhematic heart	2	2	2	
Congenital malformation of circulatory system	27	27	21	6
Ears				
Deafness and impaired hearing	8	8	6	2
Other diseases of the ear	2	2	2	
Burns	15	15	11	4
Cleft Palate and Harelip	7	7	7	
Other Morbid Conditions Due to Accidents, Poisoning, and Violence	23	23	19	4
Disease of Bones and Joints				
Osteomyelitis and periostitis	7	7	5	2
Curvature of spine	5	5	3	2
Other diseases of the bones and organs of movement	67	15	13	2
Congenital dislocation of hip	5	5	4	1
Other congenital malformations	214	28	18	10
Total	471	216	164	52

From: Bryan, Hughes. Dietary and Nutritional Problems of Crippled Children in Five Rural Counties of North Carolina, Am. J. Public Health 55(10):1545-1554, October 1965.

Table 21

TYPE & FREQUENCY OF PRIMARY CLINICAL DIAGNOSES SEEN BY NUTRITIONIST AT A DEC

DIAGNOSIS	NUMBER OF CASES
General Delays	15
Overweight	11
Environmental Deprivation	10
Cerebral Palsy	9
Mental Retardation	8
Learning Disabilities	8
Emotional Problem	7
Seizure Disorder	5
Down's Syndrome	4
Behavior Problem	4
Iron Deficiency Anemia	2
Microcephaly	2
Ectodermal Dysplasia	2
Failure to Thrive	2
Hyperactive	2
No Problem	2
Hydrocephalus	1
Von Recklinghausen's disease	1
Underweight	1
Cri-do-Chat Syndrome	1
Hypsarrythmic Syndrome	1
Bulbar Palsy	1
Autism	1
Russell-Silver Syndrome	1
Schilder's Disease	1
Translocation of Chromosome 15	1
TOTAL	103

From: Gray, Nancy. Report of Nutritional Program at Developmental Evaluation Center, Elizabeth City, North Carolina, 1979.

Table 22

PERCENT OF CASES WITH VARIOUS NUTRITIONAL DIAGNOSES

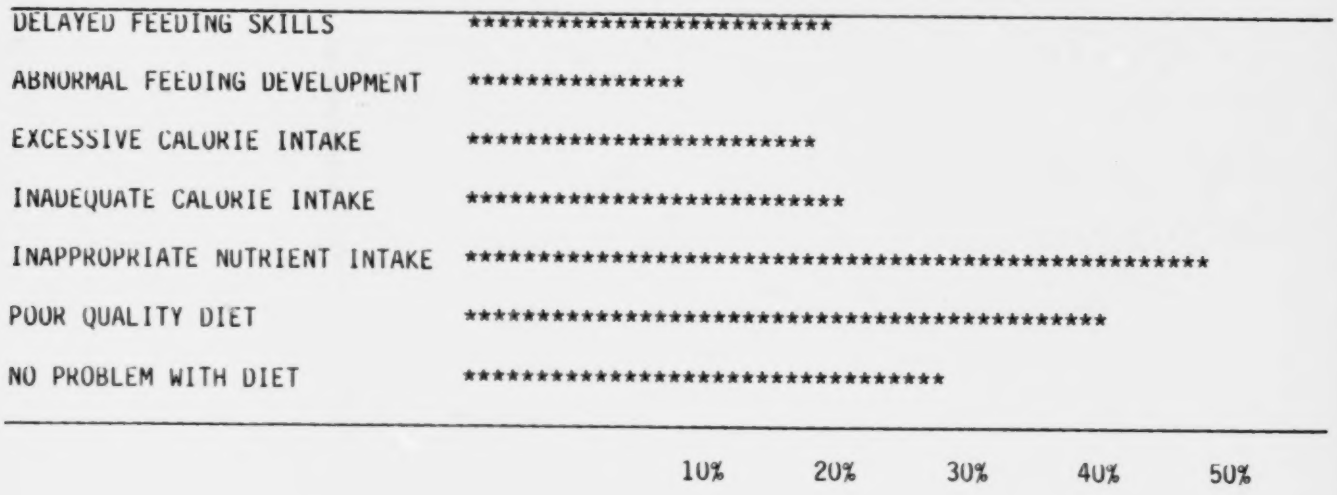
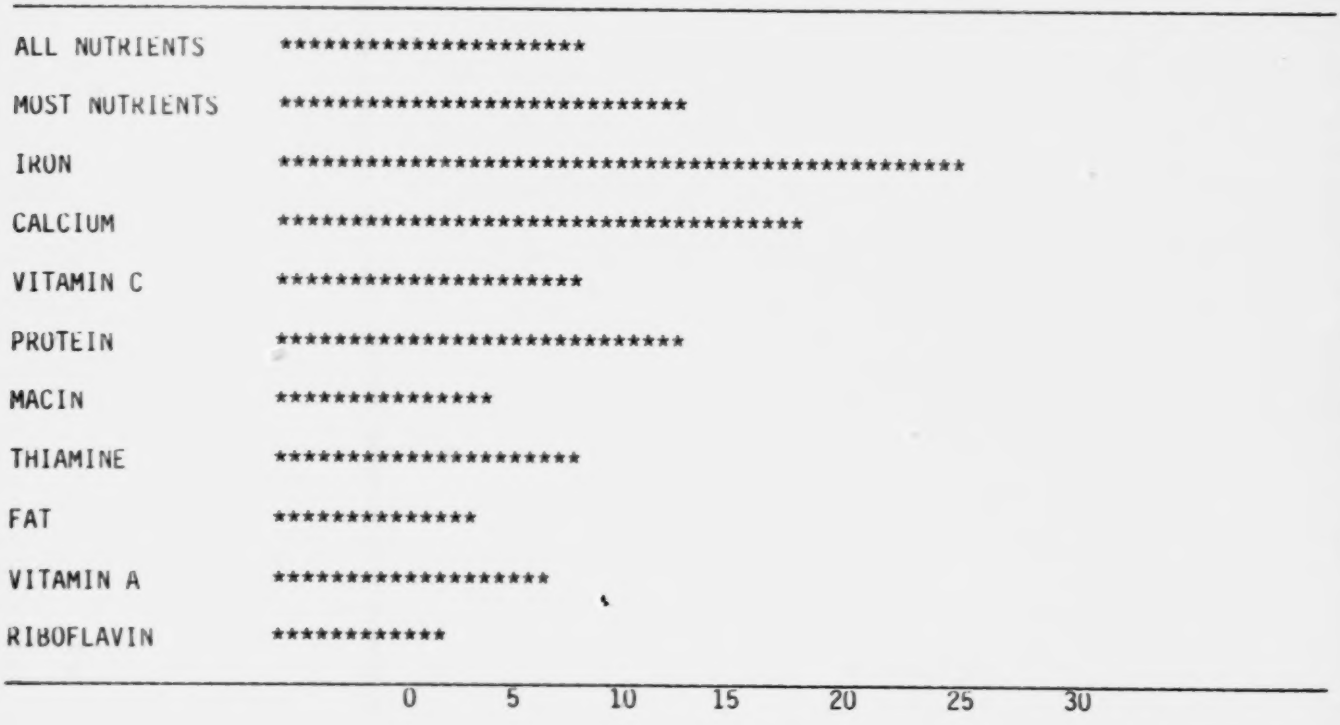


Table 23

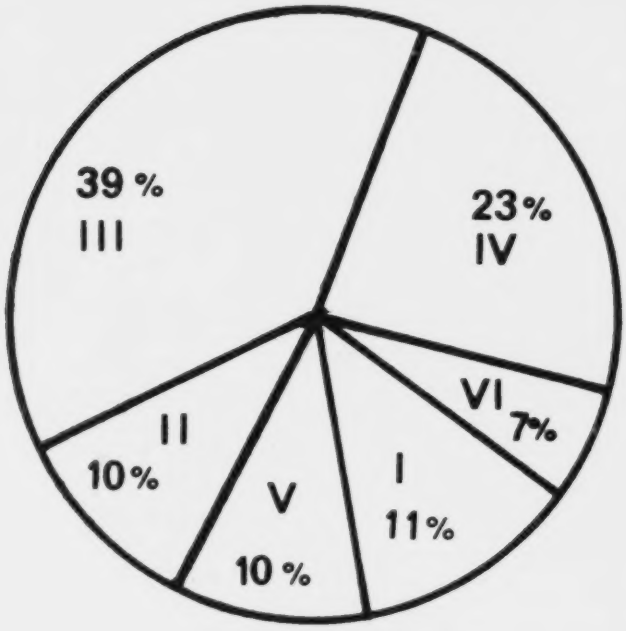
PERCENT OF CASES WITH INAPPROPRIATE NUTRIENT INTAKES



From: Gray, Nancy. Report of Nutritional Program at Developmental Evaluation Center, Elizabeth City, North Carolina, 1979.

TABLE 24

RECOMMENDATION & TREATMENT RESULTS



I. Too soon after counseling to know outcome at time measured.

II. Parent decides against counseling.

III. Parent attends session and appears to understand.

IV. Parent reports an attempt at recommendations.

V. Parent appears to have adopted recommendations.

VI. Physical changes seen (weight loss, gain, feeding skills improve, etc.)

From: Gray, Nancy. Report of Nutritional Program at Developmental Evaluation Center, Elizabeth City, North Carolina, 1979.

TABLE 14

Results of DEC Client Charts Review

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	6858						Quality of food supply
	6656		XXX				Quality of food supply
	5599		XXX	XXX			
	6654						Hyperactivity info. given out; quality of food supply
	6630						Hyperactivity info given
	6377						Ht., wt., head circum @ 5; hyperact. info given
	6197						Concern re: nutr. habits due to SES noted
	6350						Quality of food supply; no growth indications plotted
	5430		XXX	XXX			Fetal alcohol syndrome
							Rickets diagnosed 6 months; anemia @ birth
	7065						Not yet evaluated at the DEC
	4933						No growth indicators plotted
	5584						No concern
	5959		XXX	XXX			Mother wanted help with child's lacking appetite; MD noted small structure
	6353						Nutr. counseling listed as family need @ admission
	5802						10-25% wt/age, ht/age; quality of food supply
	6970						No growth indicators plotted
	5903						No concern
	6801						Dx. malnourished due to past child abuse
	5174						No concern
	6509						No concern
	6339						No concern
	6615						
	6010						No concern
	6496						Obesity apparent from photo; growth chart nl; early solids
	4371						Not yet evaluated at the DEC
	6052						No concern
	6279		XXX				Quality of food supply
	6363						Infant feeding issues crucial to case but not addressed
	7156						No concern

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TABLE 14 Cont'd

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	4504						No specific nutritional concerns
	4505			XXX			
	4513						No specific nutritional concerns
	4526			XXX			
	4541						Cleft palate; small for age; no review of feeding skills
	4846	XXX					An obese adult autistic male
	4848						No growth information (ht, wt, etc available)
	4849						No specific nutritional concerns
	4850						Diagnostic write-up of not yet available; growth parameters ok
	4857		XXX		XXX		Mention only of family physician to monitor growth
	4842						No specific nutritional concerns
	4843						A premature 9 mo old with no feeding eval documented
	4844						Twin of 4843 above; same as above; no growth info available
	4863						Growth info not available on either
	4871		XXX	XXX	XXX		
	2461						No growth indicators taken or plotted
				XXX			No ht & wt plotted; 85th% wt not addressed
	2425						Not yet evaluated
	1926						No medical or growth information collected
	2538						No growth indicators taken or plotted
	2539						Wt. 15%?; infant abuse no review of feeding practice
	1136				XXX		34.0 still on bottle; need for feeding instruction noted only
	2446						Not yet evaluated
	2500						To be evaluated for hyperactivity
	2079		XXX	XXX	XXX		Child neglect w/limited diet, need to monitor diet noted in plan but no documentation of diet review/eval
	0336						Diet reported as good, yet still taking bottle at 26 months
	2302						No growth indicators taken or plotted; referral to a public health nutr. for a sibling mentioned in chart
	2302						No growth indicators taken or plotted
	07112						Ht & wt taken but not plotted for % establishment
	2037						Growth indicaters not plotted, but no nutritional concern
	1322						Growth indicaters not plotted, but no nutritional concern

TABLE 14 Cont'd

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	2648						Not yet evaluated
	2513						Partial eval; no growth indicators
	0608						No growth indicaters taken or plotted
	2036						Not yet evaluated
	2109						Ht & wt not taken; scant diet hx dx as "good eater" all but slow eater reported by care taker
	0474						Diet reported to be "of no particular concern" when mom reported "well-balanced" breakfast & dinner, frequent snacks, potato, corn chips sent to school with child, nutritional intake
	2407						Ht & Wt indicates not taken or plotted
	2540		XXX				DSS investigated because of mal-nutrition; MD confirmed seen once by WIC nutritionists previous to DEC
	2389						No ht or wt indicators taken
	1840						Growth indicators taken but not plotted
	0383						Mother terms child "picky eater"; she have removed white flour and sugar for "control" of hyperactivity Growth indicators taken but not plotted; 50% stated; no nutrition-al concerns
	2498						Not yet evaluated
	2567						Not yet evaluated
	1737						Anemia; iron therapy had not been tolerated in past extremely small size; failure to thrive as infant-completely weaned by 13 months, totally on table foods, growth plotting not in chart for DEC visits; in past ned hx only
	5432					Duchenne Muscular dystrophy, Behavior problems, Mild MR/RD consult	Occasionally gags self and vomits - goal for appetite to improve consistently impairment of digestion due to self induced gagging and vomiting -- Physician concerned about malnourishment when removed from home
	5542					Behavior, emotional problems - RD con-sult	Describe in admission note as being somewhat obese--was on weight reduction when inpatient (1200 cal)--recommended avoiding sweets and seconds as outpatient

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TABLE 14 Cont'd

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	1175	XXX				Down's Syndrome - RD consult	1500 calorie diet --3 visits with RD
	4005	XXX				Moderate MR Macrocephaly, obesity	No intervention documented--evaluated 5/83 weight 58 lb height 49 1/2 in Age 7 years 2 months
	1865	XXX				Exogenous, obesity social and emotional immaturity, borderline low average intelligence	Obesity impairing motor skills--The need for weight management mentioned but not FU (13 years)
	5546			XXX	XXX	CP, epilepsy	Poor feeding, cal cts down by RD
	0973	XXX				Prader Willi	Mis-diagnosed as Down's until age 16; on RD-supervised diet
	3472	XXX	XXX	XXX		Mild MR	While in hosp; referred to county health dept. for diet follow-up
	5208					MR, LD, speech problems	No growth chart available
	5146		XXX		XXX	Learning Disabled	Disabled failure to thrive documented
	5455		XXX			Failure to thrive hospitalized for nutr therapy; dietitian consulted	
	5551		XXX		XXX	FTT, cp microcephally	FT admitted 1st time for nutr. therapy. PT, astimulation no prenatal care
	5655					Poor motor coordination, poor eating habits	No nutrition input noted
	5573					MR, Congenital pulmonic stenosis rule out fragile X syndrome	
	5678					Mild MR, spina bifeda with hydrocephalus	Chronic constipation - No nutrition input noted
	5549					Attention deficit disorder	
	5526			XXX		Microcephaly, mild MR, Possible downs	
	3821					Mild MR, hypotonia, Jansen's metaphysical Chondrodysplasia	
	3077					Moderate MR, possibly emerging ADD	

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TABLE 14 Cont'd

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	5281	XXX				Speech delay	Obesity
	3172			XXX	XXX	General developmental	Obesity noted in chart, but not plot-
	5453						
	5431	XXX				Emotionally disturbed	
	4966	XXX		XXX		Mild retardation Seizures, mild-moderate retardation	
	5416	XXX				Exogenious obesity	Obesity-dietitian noted "to review diet records taken at home"
	5431					Otitis media acute moderate MR	Chokes easily on solid foods, esp. meats and crackers
	1292	XXX				Severe MR, anti-social behavior, exogenous obesity	Weight reduction diet
	4993	XXX				Attention deficit exogenous obesity mild MR, HTN	No nutrition input
	5221	XXX				Estropia, ADD hyperactivity, expgempis phesotu	No nutrition input
	3788					Mild CP, hypotonia post dicoidlupus, asthma	

TABLE 14 Cont'd

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	9094					Psycho-social disadvantage	
	9145		X		X	Cerebral palsy "Need nutritional counseling" Vomits frequently - referred to nutritionist at Lenox Baker	"Dieting intake may be borderline
	9230				X	Emotional/behavioral difficulties	"Although height below 5th percentile growing steadily"
	9039	X				Psychosocial disadvan- violet behavior at school	
	8968					Seizures - peristal hypoxia behavioral problem	Medication for seizure control - Dilactin "Cavities beginning"
	8887					Dev. delays Behavior	Decayed teeth (4 years)
	8843	X				Behavior attention deficit disorder	No dental care (6 1/2 years)
	8821					Language disorder; fine motor immaturity	
	8742					Asthma, allergic rhinitis, TMJ Syndrome	
	8710					Difficulty with academic work, multiple retentions	
	8692					Academic difficulties; soft neurological signs	
	8610		X			Prenatal or perinatal brain injury; profound mental retardation; spastic quadriplegia; optic atrophy suspected Starage disease	Constipation since birth Hirschsprung's disease surgery
	8550			X	x	Down's syndrome	
	8457		X		X	Medically normal	
	8402					Language difficulty; attentional problems	

TABLE 1⍺ Cont'd

Facility/Institution	Chart No.	> 95% Wt/Age	<5% Wt/Age	<2% Head Circum	<5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
	8307					Prenatal injury dev. delayed	
	8398					Cerebral palsy "Need nutritional counseling" Vomits frequently - referred to nutritionist at Lenox Raker	"Dieting intake may be borderline
	9025				X	Hyperactive behavior	Ritalin
	2492	X				Severe LD	Dental caries
	1818					Congenital hypothyroidism w/LD & Speech and language problems	Med Desicated Thyroid
	2548-2	X					15 lb weight gain in 1 year: "Recommended that eating habits and nutrition be carefully monitored to help control weight" - no referral
	2890-2				X	Cerebral palsy organic brain damage; hyperactivity	"Recommend - Feingold & Ritalin - O.K. until something better happens along"
	2314-2		X		X	(Learning problems)	Teeth have plaque and caries
	5441					No med. problems	
	6096					Hydrocephalus temporal seizures MR	Nutritional history is described as very inadequate. Mainly eats hot dogs and junk food
	6180					Behavioral emotional problems	Reasons referred to DEC
	6182		X			Referred for behavioral problems	Past history of anemia secondary to poor nutrition
	7105-2			X		Microcephaly global retardation	
	8062					No medical problem	Referred for short attention span; difficulty in communicating
	8246					Mild to moderate MR	Dental caries

TABLE 15

Results of Residential Center Chart Review

Client No.	Nutrition Risk Indicators >95% Wt/Age	Nutrition Risk Indicators <5% Wt/Age	Nutrition Risk Indicators <5% Ht/Age	Documented Diagnosis	Other Nutritional Concerns
12149		X	X	Prof. Mr, microceph., gastrostomy, CP, blind	freq. vomiting, force fluids, force feeding
12148		X	X	Prof. MR, convulsive disorder	force fluids, has feeding problems
12178		X	X	Prof. MR, seizure disorder, CP	constipation, force fluid & food intake
12179			X	Scoliosis, Prof MR, CP, behavior problems	drug-nutrient interaction
12150		X	X	Prof. MR, CP, microceph.	tongue thrust, tantrums @ meals, constipation
12151				Prof. MR,	
12152		X	X	Psychotic; emotional probs, eye disorder	consumes inedibles; aggression @ meals
12176		X	X	CP, scoliosis, Prof. MR	no teeth, pureed diet, underweight
12155				Prof MR, hydrocephalus, seizure disorder, blind	will not drink milk
12156			X	Severe MR, seizure disorder, scoliosis	calorie-restricted diet, force fluids
12177		X	X	Prof MR, seizure disorder, hydroc. shunt, CP	gags on food, osteoporosis
12158				Prof MR, CP, microcephalic, seizures	tube fed x 5 yrs; thrashes aboout @ meals
15159				Prof. MR, CP, convulsive disord., hypotonia, diaplegia	poor fluid intake, constipation
12162				Severe MR, CP, seizure disorder, autistic	recycles food in mouth; chewing probs
12163				Prof MR, convulsive disord.	regurgitates, consume inedibles
12175		X	X	Prof MR, CP, seizure disord., orthopedic probs	gastrostomy, constip., vomiting
12173				Prof MR, seizure disord., microceph, contractures	dehydration, feeding problems
12180		X	X	Hydroceph. shunt, cleft palate, PRof MR, seizures	on CA# suppl. for brittle bones
12172		X	X	Down's Synd., hypotoria, scoliosis, seizures	chokes on food, vomiting, constipation
013351		X	X	Down's Synd., Prof MR	underweight
018817		X	X		on vit. supps., constipation
015750		X	X	Trisomy, congenital deafness	only eats liquids or solids per meal
10254				Prof. MR, seiz. disord., hyperactive	very picky eater
018840				Microceph., seiz. disord.	on dilantin, very picky eater
013355		X	X	CP, severe MR, spastic	constipation
016306		X	X	CP, blind, seiz. disorder	eats only small amts, constipation

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TABLE 15 Cont'd

Client No.	Nutrition Risk Indicators			Documented Diagnosis	Other Nutritional Concerns
	>95% Wt/Age	<5% Wt/Age	<5% Ht/Age		
013352		X		Severe MR, seiz. disorder	underwt, constip., dehydration
013354		X	X	Prof. MR, chromosomal disorder, self-abusive	consumes inedibles
013353		X	X	CP, laryngeal stridor limits O_2 supply	spits up after meals

NUTRITION RISK FACTORS DEFINED

On the following page is the listing of "Conditions of High Nutrition Risk Warranting Referral to a Nutritionist", which has been established as a result of this study. The one page format comes after the condensation of materials and ideas gathered from CCS and UAF nutritionists across the country, a review of CCS reimbursable conditions, and a lengthy review of the literature. This listing is intended for practical use by DEC and CCS staffs in North Carolina in determining client conditions warranting a referral to consultation by a nutritionist. Ideally, it should be used in tandem with the "DD Nutrition Screening/Referral Form" (page 3€) which has likewise resulted from this study effort, to ensure that all possible conditions of risk have been considered. However, the use of even one of these two reference forms in the public health DD care setting will enhance tremendously, appropriate attention to a patient's possible nutrition concerns.

TABLE 25

CONDITIONS OF HIGH NUTRITION RISK WARRANTING REFERRAL TO A NUTRITIONIST

ANTHROPOMETRIC:
- Weight/height ratio > 95th percentile
- Weight/height ratio < 5th percentile
- Height/age ratio < 5th percentile
- Head circumference < 2nd percentile
- Infant who fails to gain weight in 1st 6 weeks of life
- Documented regression of growth
- Flat growth curve over a 12 month period (in child < 18 years)

BIOCHEMICAL: Hematocrit < 31%, Hemoglobin < 10 gms

*MEDICAL: Diagnosis of:

- Juvenile Diabetes (Type I)
- Renal disease
- Cardiovascular Disease
- Malabsorption
- Hyperlipidemia
- Cleft lip/palate
- Cystic Fibrosis
- Hypertension
- Cancer
- Ulcerative Colitis
- Rickets
- Chronic kidney disease
- Chronic liver disease
- Chronic GI diseases/anomalies
- Severe burns
- Goiter
- Celiac Disease
- Inborn errors of metabolism, like:
  - PKU
  - Galactosemia
  - Maple Syrup Urine Disease
  - Cystinuria
  - Tyronsinosis
  - Hypervalinemia
  - Histidinemia
  - Fructose intolerance
  - Hypercholesterolemia
  - Glycinuria
  - Glycogen Storage Disease
  - Wilson's disease
  - Nephrocalcinosis

  (If nutrition counseling has not been provided in another medical setting)
- Long term use of:
  - Anticonvulsants
  - Behavior Modifiers

FEEDING:
- Pica
- Dysphagia
- Total liquid diet
- Longterm tube feeding/appliance use
- In infant under one year, diet contains less than 16 oz formula per day
- Vegetarianism
- Vitamin/mineral supplementation beyond 'one-a-day' level
- Consumption < 2 meals per day
- Solid foods lacking in diet of child greater than 13 months of age
- Reoccurring problems (> 3 times/month) with:
  - chewing/swallowing
  - nausea/vomiting
  - gagging
  - constipation
  - diarrhea
  - dehydration
  - behavior at mealtime

- Diet lacking in one or more of the Basic Food Groups

A referral to a nutritionist is appropriate if only <u>one</u> of these conditions is identified.

North Carolina
Division of Health Services
DU Nutrition Screening/Referral Form

Developed by,
The Colorado Department of Health

Child _____ Screener _____
Birthdate _____ Age ____ Agency _____
Parent _____ Screening Date _____
Address _____ Referral: Not Needed ____ Needed ____
_____ Referred to _____
(name) (title)
Diagnosis _____ Agency _____
Concern _____ Date _____
Phone _____

Directions: Review items with child's parents. Check concerns. Explain checked items under Comments. Checked boxes suggest that the child may have a nutrition related problem. Refer forms with checked boxes to a nutritionist to determine if further nutrition assessment and counseling are appropriate.

Family

☐ Parent questions/concerns about the child's nutrition: _____

☐ mealtime behavior problems
☐ problems feeding child
☐ SES affecting food supply

Medical

☐ Practitioner concerns about child's nutrition _____

☐ appears thin
☐ appears overweight
☐ recent weight gain
☐ recent weight loss
☐ dental problems
☐ often seems tired/very active
☐ anemic
☐ allergies
☐ vomiting
☐ frequent/infrequent urination
☐ diarrhea
☐ constipation
☐ poor appetite
☐ resists food
☐ Edema
☐ Other _____

Feeding Skills

☐ does not finger feed after 10 months
☐ unable to feed self after 3 years
☐ not weaned to cup by 24 months
☐ special feeding appliance/positioning used
☐ tongue thrust after 6 months
☐ drooling after 18 months
☐ sucks poorly on nipple
☐ chokes on liquids
☐ chews with difficulty or not at all after 2-1/2 years
☐ dislikes solids after 1 year
☐ gags or chokes on solids
☐ length of meal is greater than 45 minutes
☐ swallows with difficulty

Diet

Eating Only:

Texture
☐ blended/pureed junior foods after 13 months
☐ chopped/junior after 1 year
☐ soft table food after 3 years

Infant
___ formula fed (brand) _____ ☐ without iron ___ breastfed

☐ formula not prepared as follows:
___ concentrate: one part water to one part concentrate
___ powdered: 1 scoop powder to 2 oz. water (excludes formulas for metabolic disorders)
___ ready to feed: serve as is; do not add water

☐ amount of formula/24 hours - less than 16 oz. or more than 48 oz.

Quality of the Child's Diet

Number of servings of the following foods child eats on most days:

	Recommended		Recommended
____ Protein (meat, eggs, poultry, fish, beans)	(2)	____ Fruit and Vegetable	(4)
____ Diary (milk, cheese, yogurt)	(3)	____ Vitamin C Enriched Juice	(1)
____ Water		____ Bread and Cereal	(4)
		____ Iron-Fortified Infant Cereal (infant only)	

COMMENTS (explain checked items): _____

DHS _____ 1984

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RECOMMENDATIONS

State DD Branch

- The State DD Branch shall consider hiring one state DD nutritionist during fiscal year 1985, and four regional DD nutritionists in fiscal year 1986, as a result of the information contained in this report. The proposed responsibilities of those occupying the positions recommended are outlined on pages 49-52. The intent is for structured, gradual enhancement of a nutrition component within the multimillion dollar DD public health effort in North Carolina (see pages 46-48 for further explanation).

- The State DD Branch shall consider reimbursing for ambulatory/inpatient nutrition services through the CCS Program.

- The DECs shall consider establishment of a fee for nutrition consultation, and the incorporation of such into their sliding fee schedules.

- The State DD Branch shall sponsor training to DEC and CCS personnel in the use of the DD Nutrition Screening/Referral Form and procedures for its use. An inservice on the role of nutrition in the care of handicapped children shall be included as a part of this training. Appropriate state, regional and UAF nutrition staff shall be responsible for the content of this training session. The DD Branch shall ensure that appropriate local personnel are invited and attend.

- DECs, with the exception of those having a nutritionist on staff, shall be instructed to complete a DD Nutrition Screening Form on each client evaluated, for inclusion in their agency's patient record and for referral to a nutritionist when appropriate and possible.

- The Genetics Program shall give consideration to requiring a nutrition consult to parents wanting more children where prenatal health/nutritional status of the mother appears to have been a concern in the development of previous offspring.

- Any DD nutrition specialist first hired at the State or regional level shall work with Genetics Program personnel to establish a listing of high risk nutrition criteria appropriate to their program which will ensure nutrition referrals as needed and when appropriate.

- When revamping their DEC computerized management information system, the DD Branch shall consider inclusion of a coded classification for nutrition problems among their data requirements. The DHHS' published "Nutrition Problems Classification for Children and Youth" shall be considered as a possible coding format for nutrition conditions encountered.

- The DD Branch shall consider requiring a nutritionist on at least a part-time consulting basis, as one of the staffing requirements necessary for funding of a DEC, to be effective after Fiscal Year 1986 (i.e., a required inclusion within core teams).

- Consideration shall be given to placing the State level nutritionist position within the Clinical Unit of the DD Branch.

- The DD Branch shall consider inclusion of local nutrition specialists within the case management teams proposed for eventual inclusion in DD catchment areas.

  In revamping the number, location, and staffing requirements for CC Contracted Clinics within DD catchments, the Branch shall consider requiring a nutritionist as part of the individual clinic teams for those specialties to which nutrition is relevant. Such a requirement could be incorporated into clinic guidelines and/or CCS standards regarding teams.

Suggestions for Deriving Monies Adequate to Support Nutrition Services

- Additional revenues to be realized beginning in FY 1985, due to the State Division of Medical Assistance's change in medicaid regulations, to affect both DEC and CCS Program revenues (and entire DD catchment areas), shall be considered as funds possible for use in funding one state level and four regional level nutritionist positions.

- Consideration shall be given to making revenues realized locally in DECs through both new mandatory client billing requirements and the medicaid change cited above (revenues estimated at approximately $12,000 per DEC in FY 1985 by the State Office) available for use in the local, part-time hiring of nutritionists by DECs.

- As current positions come vacant at the local (DEC), regional and/or State (management) level, the DD Branch Head shall consider requesting reclassification of one or more positions to allow for the placement of nutritionists, at least at the State and Regional levels.

- The DD/ Nutrition coordinating position within the Central Office could be requested as a temporary (two year) position, rather than a permanent one, for ease in hiring within the State Government System.

- The DD Branch Head shall consider requesting expansion monies through the Department of Human Resources for the placement of a DD nutritionist within the Clinical Unit of the Branch, and eventually for the regional positions necessary to institute a nutrition component into DD care.

State Nutrition and Dietary Services Branch

- The State Nutrition Branch's Nutrition Standards of Care Committee shall develop standards of care for as many DD-related conditions as possible in the course of their work. Nutrition personnel hired at the state and/or regional level to be responsible for nutrition service in developmental disability programs shall take responsibility for developing care standards for the conditions which remain undone by the committee, and shall be responsible for the implementation and enforcement of the standards.

- The listing of Nutritionally-Related Medical Conditions Reimbursable through the Crippled Children's Program shall be distributed to public health nutritionists in county health departments for their use in identifying children on the Crippled Children's roster (also delivered to county health departments) in need of nutrition services.

- Local health department nutritionists shall be instructed to document in writing, and send to the appropriate DEC, CCS Clinic or private medical provider, the consultation they provide to any patient referred to them from those agencies.

- The Nutrition Directors of the Division of Health Services and the Mental Health, Mental Retardation and Substance Abuse Division shall consider coming together to delineate the role and responsibilities of the four DD regional nutritionists proposed for hire.

- The Area Health Education Center shall be considered by the State DD nutritionist as one possible source of qualified (temporary) manpower when assisting local DECs to secure a nutritionist.

- The Nutrition and Dietary Services Branch shall work with the UNC School of Public Health's Nutrition Department to explore the feasibility of arranging for a master's level nutrition fellowship specializing in DD. Such a cooperative arrangement would:
  a) provide additional DD/Nutrition manpower at the state, administering level of public health,
  b) serve as an additional method of training such a specialist,
  c) be of assistance, in the early years, with more rapid development and implementation of a DD nutrition component.

- The Nutrition Branch shall recommend and ensure that the nutritionists hired at the regional and state levels as a result of this needs assessment are of the 'Nutrition Program Consultant' (Pay Grade 72) classification under the State employment system.

The State Division of Health Services

- The State Division of Health Services shall advocate for third party reimbursement of ambulatory nutrition services by private and public (medicaid) insurers.

- The State Division of Health Services shall consider initiating or at least supporting legislation requiring folic acid supplementation early in pregnancy if and when the evidence supporting the role of folic acid in prevention of spina bifida becomes scientifically and medically sound enough to do so.

- The State Division of Health Services shall establish the direct and indirect lines of authority relative to any nutrition positions created at the state or regional level as a result of this study. Recommendations are that a single state position be created with DD funds, for placement in either the DD or Nutrition Branch. The regional nutrition positions, when created, are recommended to be direct service jobs first and foremost, with a consultation role only to those DECs, CCS sites employing their own nutritionist(s). However, to be most widespread in their effectiveness and impact, it is suggested that the creation of these regional nutrition positions be a joint effort between the Division of Health Services and the Division of Mental Health, Mental Retardation and Substance Abuse. This would allow all of the various DD-related programs in need of enhanced nutrition input to benefit from the creation of just four positions. Certain of the programs, especially those day and temporary residential services under the Division of Mental Health will require involvement on a consulting basis only. Thus, some coverage of the broader array of programs and direct service provision to DECs and some CCS sites in each of the regions appears feasible. The Division of Health Services shall take responsibility for initiating discussion of this possible joint arrangement.

- The State Division of Health Services shall negotiate to have nutrition services included as a reimbursable expense in DEC and CC clinics, under their memorandum of understanding with the State Division of Medical Assistance.

The DDDL

- The DDDL (UAF) nutritionist shall be available to participate in the organization of training to nutritionists hired at the state, regional and local levels for service as specialists in developmental disabilities. The frequency, duration, and format of such trainings shall be agreed upon by the State Nutrition Branch and the UAF nutritionists as DD monies come available to hire one state, four regional and perhaps other locally-initiated DD nutrition positions. In general, the UAF should more obviously avail itself as a training site for nutritionists, i.e., those to be employed in jobs of this specialty; with a UAF in the state any lack of nutritionists with DD expertise should be a remediable, temporary problem. If the numbers of persons being hired grows locally, a semi-annual, formalized training program shall be offered, with funding from the state office, or an employer-paid enrollment fee adequate to cover the cost of the training.

- In locations where nutritionists are currently on staff, (i.e., the DDDL and Amos Cottage) decisions about the need to evaluate any particular child should include consideration of their condition as a normal child, as well as in light of any disability. I.e., attention to fat, salt, sugar, additive content and overall quality of the diet should be given, even in those cases where nutrition is not related to the disability per se.

- On the years when pre-doctoral fellowships are available through the Nutrition Section of the DDDL, the UAF shall work closely with the DD Nutritionist at the State Division of Health Services in identifying an appropriate fellow, and to plan for the fellow's ongoing involvement in DD-related nutrition activities of the State Division of Health Services.

- The DDDL administrator, through his involvement with the consortium of southern UAFs, shall make other state centers attuned to the needs for training of DD nutrition specialists prepared to enter the public health DD/nutrition workforce. Relevant portions of this report shall be brought to the attention of the consortium.

Local DEC/CCS Agencies

- The DECs shall, following detailed instruction from the State Office, implement usage of the DD Nutrition Screening/Referral Form and the list of "Conditions of High Nutrition Risk Warranting Referral to a Nutritionist".

- All medical personnel involved in the direct care of developmentally delayed or handicapped children shall give greater attention to situations where formula supplementation (including total parenteral nutrition) may be indicated for optimal nutriture of a child. (Numerous conditions of underweight have been identified, and formula supplementation has been observed not to be routinely considered).

- Any DEC or CCS specialty clinic intending to use the nutrition expertise available at a county health department, shall secure in writing an interagency agreement delineating that service and the responsibilities of each agency.

- DECs and CCS centers interested in staffing a fulltime, part-time or consulting nutritionist shall so indicate this to the State Division of Health Services DD Branch staff, either through a funding request within the annual grant application, or by other means (e.g. letters and phone calls) as appropriate.

- DECs and CCS centers interested in staffing a fulltime, part-time or consulting nutritionist as a result of this study shall conduct their own agency budget review to determine if there are any contract monies, other salary monies, or staffing ratios which could be shifted to accommodate the need for a nutrition specialist in the current fiscal year.

- Local DECs, CCS and Genetic Programs shall give thought to referring patients in need of diet counseling to private nutrition consultants. Those private practitioners will need to be contacted directly to determine their availability, and to establish a reliable referral method.

- Local administrators shall review the summaries of agency site visits to learn in greater detail of the identified obstacles to/possibilities for incorporating nutriiton evaluation and client care.

- Local DEC/CCS administrators shall recoqnize, through a review of the program assessment questionnaire and use of the DD Nutrition Screening/Referral form that existing staffs can and do at times presently provide various components of nutrition care. Using the information in this report, agencies shall devise a plan for enhancing staff awareness and understanding of nutrition issues. Inservices and general staff awareness can greatly enhance consistency in considering a patient's potential feeding/dietary problems.

Local Agencies (cont'd)

- Local DECs and CCS centers shall assess the accuracy and acceptability of their existing height and weight measuring equipment, as well as current staff techniques for taking those measures and plotting the information. Scales and centrifuges (if on site) shall be professionally calibrated once annually to ensure accuracy. A staff inservice on appropriate, standard, methods for taking anthropometric measures shall be considered if warranted.

- Local DECs and CCS centers shall post the table entitled "High Risk Nutrition Conditions, Warranting Referral to a Nutritionist" in an appropriate place within their clinics.

- Local DECs shall maintain a record of the number of referrals made to a nutritionist after implementation of the "Screening/Referral" and "High Risk" forms.

Other State Agencies

Department of Public Instruction

- The Department of Public Instruction, because it regulates the food service to large numbers of handicapped children through the educational funding and meal reimbursement to developmental day centers, certain of the institutions, and to children in the public school setting, shall give consideration to ensuring, through regulation, the appropriate, special food consistency and other feeding needs of handicapped children.

Division of Mental Health, Mental Retardation and Substance Abuse

- The Division of Mental Health, Mental Retardation and Substance Abuse shall consider the provision of an annualized nutrition training seminar for the local staffs of Early Intervention Programs statewide. These training sessions could be arranged through the nutritionist at the state level in the MR Division if possible, or perhaps more feasibly through the four proposed regional DD nutritionists whose positions would be designed to service programs of the MR Division as well as those of the Division of Health either permanently or on a temporary test basis.

- See Recommendation # 3 under State Division of Health Services

- UNC School of Public Health

- See Recommendation # 6 , Nutrition and Dietary Services Branch.

- The Nutrition Department at the UNC School of Public Health shall consider offering an elective course within their curriculum at the master's level on nutritional considerations/care of the developmentally disabled.

D.D. Nutrition Program Plan

Goals: To provide quality nutrition services to North Carolina's developmentally disabled children.

To institute within the State Division of Health Services, at the state, regional and local level, an operational method for ensuring attention to the nutritional concerns of children served within the DECs, and CCS and Genetics Programs.

Objectives:

1. A state D.D. nutrition coordinator (registered dietitian with master's degree and experience) will be hired with D.D. branch funds, in cooperation with the Nutrition branch, by January, 1985.

2. All recommendations as a result of the D.D. nutrition needs assessment study will be reviewed and considered during FY 1984-85.

3. The D.D. Nutrition Screening/Referral Form will be submitted, following any desired revisions, to the state government's Forms Review Committee for approval of its use. Appropriate D.D. and Nutrition branch staff will decide how and when local DEC and CCS staffs will be instructed on its use within the current fiscal year.

4. The D.D. nutrition coordinator, once in place, will incorporate the suggested inclusions for her job description (page 40) into her work responsibilities.

5. The D.D. Branch Head will examine the existing D.D. budget within the Division of Health Services, to determine which and what amount of funds can be devoted to this effort. Suggestions are included on page 39.

6. Individual negotiations with certain DECs and CCS groups, for the hire of their own nutritionists as already-funded pilot projects, will be undertaken in FY 1984-85.

7. All DECs and CCS sites will be provided with a list of the 'High Risk Nutrition Conditions Warranting Referral to a Nutritionist', for posting at clinic sites, during FY 1985.

8. A listing of high risk nutrition criteria relevant to the Genetics Program will be drafted by the DD Nutrition Coordinator, in cooperation with Genetics Central Office Program staff, during FY 1985. This listing will be distributed to all genetic counseling sites by August 1, 1985.

9. During FY 1986, the DD Nutrition Coordinator and the Nutrition Branch Head of the Division of Health Services, shall meet with the Nutrition Director of the Division of Mental Health, if the regional nutrition consultant positions are to be shared between the divisions, to delineate the roles and responsibilities of the consultants and their relationship to state and local offices.

10. Attention shall be given, by the State and Regional DD nutrition consultants, during FYs 1985 and 1986, to those opportunities which exist in local health departments for some integration of Nutrition and CCS staffs.

11. The State DD nutrition coordinator shall work with the Nutrition Standards of Care Committee, and through his/her own initiative, to ensure that all components of a 'quality assured' nutrition program, as addressed in one section of this report, are in place prior to widespread direct service involvement of regionalized and/or local nutritionists in DD settings.

12. Eventual placement of one nutrition consultant per DD catchment, rather than just the four regional direct service providers, shall be considered as revisions in the catchment concept occur, or after two years of regionalized nutrition service.

13. The DD Branch shall ensure that any nutritionist placed in the state, regional, and/or local level DD nutrition consultant positions will have either prior or on-the-job, formalized training in the area of developmental disabilities.

Explanation of Proposed DD Nutrition Component Implementation Process

Fiscal Year 1985:

A Nutrition Consultant would be placed within the Clinical Unit of the DD branch. He/She would undergo any necessary training, and then begin to carry out the recommendations and objectives described in preceding pages. Year one would be spent in the establishment of protocols for care, in educating/training local DEC, CCS, Genetic and county health department staffs regarding the need for DD nutrition services, and in nutrition screening and referral techniques. At the same time, he/she would initiate and facilitate local efforts to place, with existing allocations to DEC and CCS groups, individual, probably part-time nutrition specialists. The DD Nutrition Coordinator would delineate the job requirements and formalized training process for those regionalized full-time and few locally placed part-time nutritionists to come aboard in fiscal year 1986. Negotiations with the Division of Mental Health will need to be undertaken, should the DD branch elect to seek Department of Human Resource approval for sharing of the regional direct service providers with the MR Division.

Fiscal Year 1986:

In the second year, the regional DD/Nutrition specialists, following appropriate training, would involve themselves heavily in direct client service at the DEC and CCS Clinics within their region. Thus, direct client benefit would be assured in this first year of major program expense. A good deal of sophistication and definition could occur in the local nutrition care being provided, and agencies/clinic sites with greatest volume of need for nutrition service would emerge. In the second and third year of the regionalized direct nutrition service, the DD regional nutrition consultants could attempt to 'spin off' certain of the DEC or CCS locations where the heaviest demand for a nutritionist had been demonstrated, via the local hiring of a full or part-time nutritionist through locally granted funds. To those agencies where local nutritionists are placed, the regional nutritionist would become a consultant in the sense that other regional staff persons consult; in other locations she would continue as the direct service provider. Eventually, if each DD catchment comes to have its own nutrition consultant, to cover all concerns within that catchment, including CC, then the regional positions could be phased out or left in place as true regional consultants, providing consultation as opposed to direct services.

Inclusions for the Job Description of the State DD Nutritionist

- Serve as initiator and liason in bringing the directors of CCS Clinics together in the large metropolitan areas of North Carolina, to arrange for their hiring of a nutritionist to be shared between the clinics. The most obvious locations for cultivation of such a cooperative arrangement are:

  UNC, Chapel Hill
  Duke, Durham
  Bowman Gray, Amos Cottage, Winston Salem
  Greenville DEC
  Charlotte DEC

- Establish a listing of private nutrition consultants for use by DECs in making their own arrangements to hire a consulting nutritionist. Initiate meetings with individual DEC directors to encourage such a hiring and suggest qualified persons.

- Locate and distribute appropriate DD nutrition education materials to regional and local nutrition personnel.

- Contact the Master's Consortium in Dietetics at the University of North Carolina, Greensboro (UNCG), to discuss enhancement of their existing manpower training program. Work with them to continue their chosen emphasis on nutritional care of the mentally retarded so as to make it a formal training option for nutritionists interested in the specialty, and a manpower resource for DECs. Ongoing placement of UNCG practicum students for a 1-2 month period is one option of potential benefit to DECs at no cost.

- Take responsibility for overseeing/carrying out the recommendations made as a result of this study.

- Work directly with the Nutrition Branch's Nutrition Standards of Care Committee to develop certain of the needed care protocols specific to DD conditions. Independently, devise the policies, procedures, job descriptions and training materials to be used by the four regional nutrition consultants scheduled to come on board in fiscal year 1986.

- Plan a statewide training session for DEC, CCS and Genetics Programs separately, introducing and initiating the use of the DD Nutrition Screening/Referral form. This can be undertaken in the first year, to:

  a) establish in the minds of the local professionals the need that does exist for attention to nutrition issues.

  b) encourage them to seek their own, private nutrition consultant to meet the need.

- Consider writing a SPRANS grant request for fiscal year 1986 for putting the full program (including the four regionalized nutrition providers) in place. Discuss other potential grant sources with Division of Health Services personnel. Oversee the writing of any such request.

- attend national meetings relevant to the nutrition care of developmentally disabled children, so as to ensure that practices of this care in North Carolina are kept current.

- initiate coordination meetings between Division of Health DD nutrition staff and the nutrition staffs of other government divisions, DPI and MR for example, to ensure thorough but unduplicated coverage of local agencies deserving a nutritionist's attention.

Inclusions for the Job Descriptions of the 4 Regional DD Nutritionists

- Take responsibility for serving the direct nutrition counseling needs of children enrolled in any DEC, CCS or Genetic Program in the region. This will include:

    a) training DEC, CCS and Genetic staffs to screen children for nutritional problems and schedule them for a session with a nutritionist. This position will serve as the counseling nutritionist for all those programs, except in those situations where the regional DD nutritionist has successfully negotiated for the local, full or parttime placement of a nutritionist. In those cases, the regional nutrition consultants will merely advise the locally placed nutritionist.

    b) establishing a set schedule of counseling/nutrition assessment hours at the various DEC, CCS and Genetic locations so that the agencies can fill those times with patient appointments. This schedule shall be arranged so as to have the nutritionist available in as many cases as possible, on the busiest clinic days at each location.

- Organize and present regionalized nutrition inservices to CCS, DEC, Genetics and MR staffs.

- Develop a method of ongoing DD client care evaluation which will demonstrate quality of care and improved outcome.

- Consult and/or become involved in limited but more direct service to the programs under the Division of Mental Health, Mental Retardation and Substance Abuse which are not currently staffed by dietitians, i.e., the Developmental Day Centers and the Early Intervention Programs. Such involvement would be under the supervision of the State MR Division's Nutrition Director.

- Provide inservice nutrition training to the home health care personnel who make home visits to developmentally disabled children within each of the regions.

- Consult with the region's Genetic Consultant(s) to identify nutrition needs of the population served by the consultant and to establish a plan for delivery of service to those identified.

- Demonstrate the role of a nutritionist by providing clinical nutrition services including evaluation (assessment), dietary counseling, follow-up and/or referral to clients. As the demand/need for nutrition services increases at any DEC, CCS, or Genetics location, initiate negotiations for greater time involvement and local payment/placement of an individual nutritionist to replace the occasional, regional involvement.

- Provide nutritional evaluations on Crippled Children clients in the regions who have been screened and scheduled for a needed nutrition evaluation.
- Participate in the interdisciplinary staffing of DEC client evaluations; integrate all pertinent nutrition information.
- Train DEC, CCS and Genetics staffs to do preliminary nutrition screening.
- Consult to the Developmental Day Care Centers in the Region
- Participate with any (DEC or CCS) team conducting feeding evaluations; give nutrition input to this team
- Collect data to identify types of clients seen, success of follow-up; continue to document the need and effectiveness of nutrition services.
- Participate in regional Nutrition and Dietary Services Branch meetings.

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